Telemedicine For ALS Care: A 'House Call' by the Multidisciplinary Team

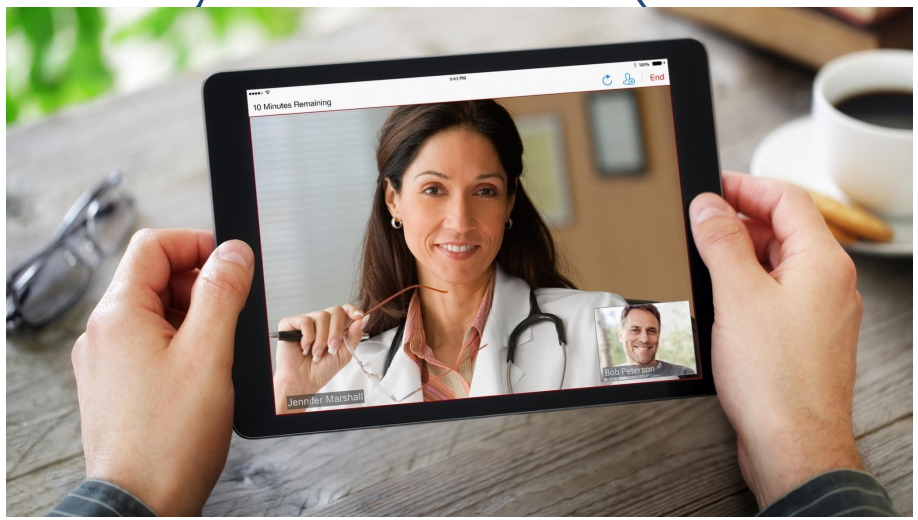
Zachary Simmons, MD
Director, ALS Program
Department of Neurology
Penn State Health
Hershey, PA

TERMINOLOGY

- Telemedicine: Remote clinician/patient interaction.
  - This is the traditional way most of us think of telemedicine.
- Telehealth: Provision of a broader range of services remotely.
  - Collection of data on respiratory function, gait/falls, muscle strength, speech quality and speed, etc.
- For the purposes of this talk, telemedicine and telehealth will be considered equivalent.

Transmission

- Synchronous
  - Information transmitted in both directions during the same time period.
  - Binary transmissions between patient/caregiver and health care provider, or multi-person, with other providers or family members on the conference simultaneously.
- Asynchronous (store and forward)



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Patient Locations

- In their homes (the model used here)
- In other physicians' offices
- In health care facilities such as an emergency
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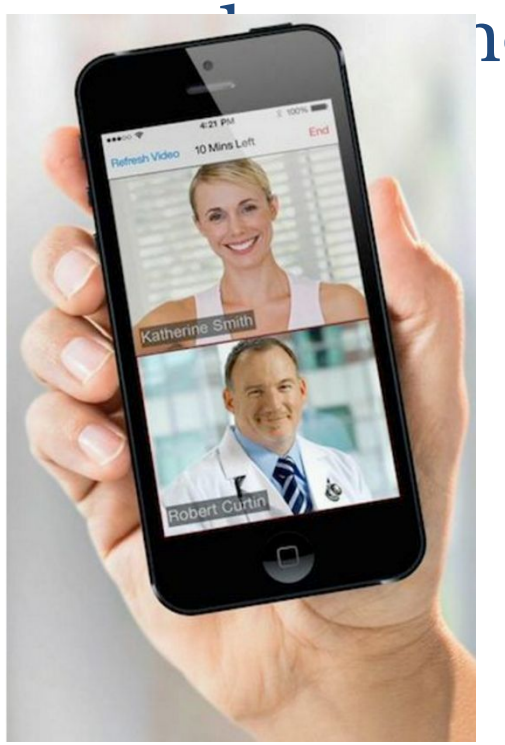
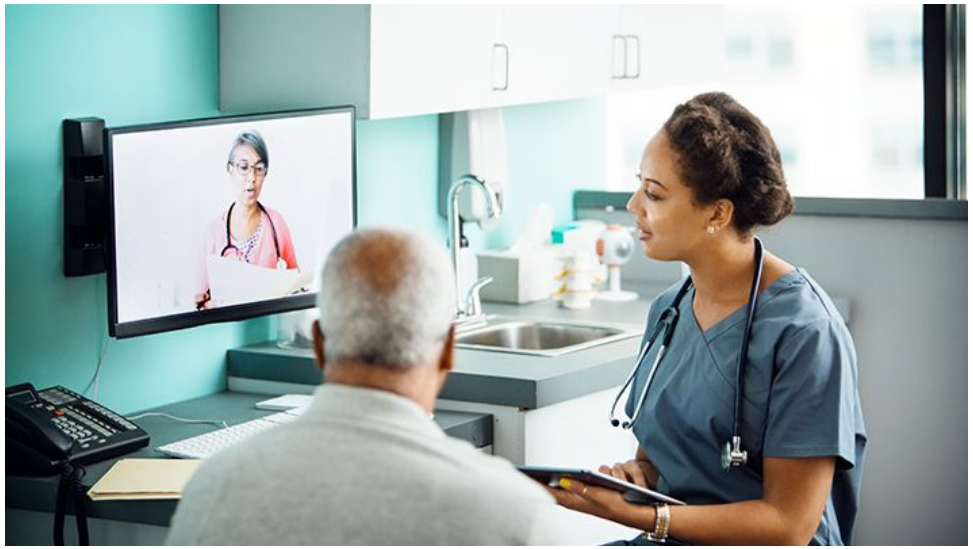




Needed

- Smart phone and application
  OR
- Tablet and application
  OR
- Computer with a camera, internet connection, and web-based system

What is the Gap Telemedicine Could Fill?

- Has the potential to improve the efficiency of health care while reducing the burden on patients
- Average 20 day delay to obtain a 20-minute physician appointment
  - Including travel and wait times, appointments take an average of 2 hours
- This has resulted in studies of telemedicine:
  - Feasibility
  - Acceptability
  - Outcomes relative to in-person care

Source: Ray KN, et al. JAMA Intern Med 2015; 175: 1983-1986

ALS Standard of Care: The Multidisciplinary Clinic

- Patients are seen approximately every 3 months for evaluation by a multidisciplinary team
- Pulmonary function tests are performed at these visits
- Extends survival
- Likely improves quality of life

Patient Perceptions of Multidisciplinary ALS Clinic

- Positives
  - Integrated care ("one-stop shopping")
  - Expertise of healthcare providers
  - Research and clinical trials
- Negatives
  - Travel distance
  - Long, exhausting day
  - Total time and wait time between providers

Source: Stephens HE, et al. Amyotroph Lateral Scler Frontotemporal Degener. 2016;17:55-61.

Additional Data Reinforce That Travel and Time Pose Barriers to ALS Clinic Attendance

- Nearly half of patients with ALS in the US live more than 50 miles from an ALS center, and a quarter live more than 100 miles away
- Family caregivers spend an average of 11 hrs. per day caring for an individual with ALS. Physical and emotional burden worsens with disease progression

Sources:
Horton DK, et al. Amyotroph Lateral Scler Frontotemporal Degener 2018;19:126–133.
Murphy V, et el. Amyotroph Lateral Scler 2009;10:147–53.
Hecht MJ, et al. Palliat Med. 2003;17:327–33.

Ideal ALS Care Would Maintain Benefits and Reduce Burdens

- Establish more multidisciplinary clinics? A challenge
  - Limited supply of health care providers with expertise in ALS
  - Smaller centers would see fewer patients, leading to less experience and expertise by providers
  - Some areas are too sparsely populated to support ALS clinics
- Telemedicine has the potential to fill this gap
  - Preserving multidisciplinary care and reducing time and travel

Feasibility And Acceptability of Telemedicine for ALS

Supported by Several Studies of Synchronous Videoconferencing

Brisbane, Australia

- Two tertiary referral hospitals with multidisciplinary ALS clinics
- Telehealth visits reported for 38 patients, seen an average of 3 times each at intervals of 3-4 months
- Average driving distance per telehealth event: 612 km (386 miles), range 158-1824 km (98-1133 miles)
- Major problems addressed were symptom based; respiratory and palliative concerns were predominant.
- No assessment of health outcomes

Source: Henderson RD, et al. Med J Aust 2014;201:31

Mass General, Boston, USA

- Retrospective chart review of video televisit encounters at MGH ALS clinic 09/2014 to 01/2016
- Encounters with a physician or nurse practitioner (not a multidisciplinary team)
- 97 patients in their homes
- Median distance 211 miles
- Average visit 32 minutes

Mass General (2)

- Patient characteristics: many had advanced disease
  - One-half ambulatory
  - One-third using NIV or gastrostomy
  - 23% had tracheostomy
  - 12% receiving hospice services
- Most commonly addressed: medication management, goals of care, research, equipment.
- Conclusion: video visits are feasible

Source: Van De Rijn M, et al. Amyotroph Lateral Scler Frontotemporal Degener 2018;19:143-148.

Penn State, Hershey, PA

Penn State Health OnDemand ALS

- Prospective Study: March 2016 to Feb 2017
- Inclusion Criteria:
  - Had attended at least one in-person ALS multidisciplinary clinic visit
  - Clinically definite, probable, probable laboratory-supported, or possible ALS.
  - Had necessary software and hardware
- Encounters with multidisciplinary team
- 30 patients in their homes, 33 telemedicine visits
- Travel time to clinic: About equally divided into 3 groups:
  - Less than 60 min, 60-120 min, more than 120 min
- Visit length: 15-30 minutes per provider (multiple providers/visit)

Penn State (2)

- What patients and caregivers liked:
  - Absence of travel, being in their home, time savings, reduction in fatigue, increased comfort.
- What patients and caregivers disliked:
  - Impersonal, problems with video/audio, lack of privacy, not getting out of home
  - Four caregivers expressed concerns about lack of a physical examination, although no patient did so.

Source: Geronimo A, et al. Amyotroph Lateral Scler Frontotemporal Degener 2017;18:555-561

Penn State (3)

- What healthcare providers liked:
  - Patients more comfortable and less stressed, ability to see patients who would otherwise not be able to be seen, patients were more open and talkative, patients could be observed in their homes.
- What healthcare providers disliked:
  - Problems with video/audio, no physical examination, no cues from body language, less of an emotional connection.
- Overall, feasibility high and satisfaction high as rated by patients, caregivers, and healthcare providers

Source: Geronimo A, et al. Amyotroph Lateral Scler Frontotemporal Degener 2017;18:555-561

Outcome Data

Very Limited For ALS Synchronous Videoconferencing

Cleveland VA ALS Center

- Patients with ALS were given choice of in-person or telemedicine care
- Patients were in their homes
- Evaluations always included physician and nurse. Other providers were based on assessment of patient's needs
- PFTs or modified barium swallow performed locally prior to telemedicine visit if deemed necessary.
- Quality of care was based on AAN quality measures
- Outcomes were survival, disease progression, malnutrition
- Findings: Same quality of care. Similar outcomes.

Source: Selkirk SM, et al. Amyotrophic Lateral Scler Frontotemporal Degener 2017;18(5-6):324-332.

Now that telehealth is available, is likely feasible and acceptable, and may result in high quality care with good outcomes, how do we incorporate it into routine ALS patient care?

Roles of Telemedicine in ALS Care

- As a substitute for regularly scheduled visits with the multidisciplinary team
  - For those who can no longer travel to clinic
- To decrease the length of an in-clinic visit
  - 1-on-1 videoconferencing with selected team members prior to the in-clinic visit
  - Particularly relevant for encounters not requiring physical contact.
- As needed for urgent matters
  - 1-on-1 videoconferencing with selected team members
  - Triggered by communications from patients or caregivers
  - Examples: 1) psychological crisis: mental health professional; 2) visualize and discuss transfer or personal care techniques: PT or OT; 3) visualize and discuss bedsore or problem with feeding tube: nurse; 4) discuss goals of care or genetic test results: physician

Based on these considerations, we have now incorporated ALS telemedicine fully into our ALS clinic in these roles

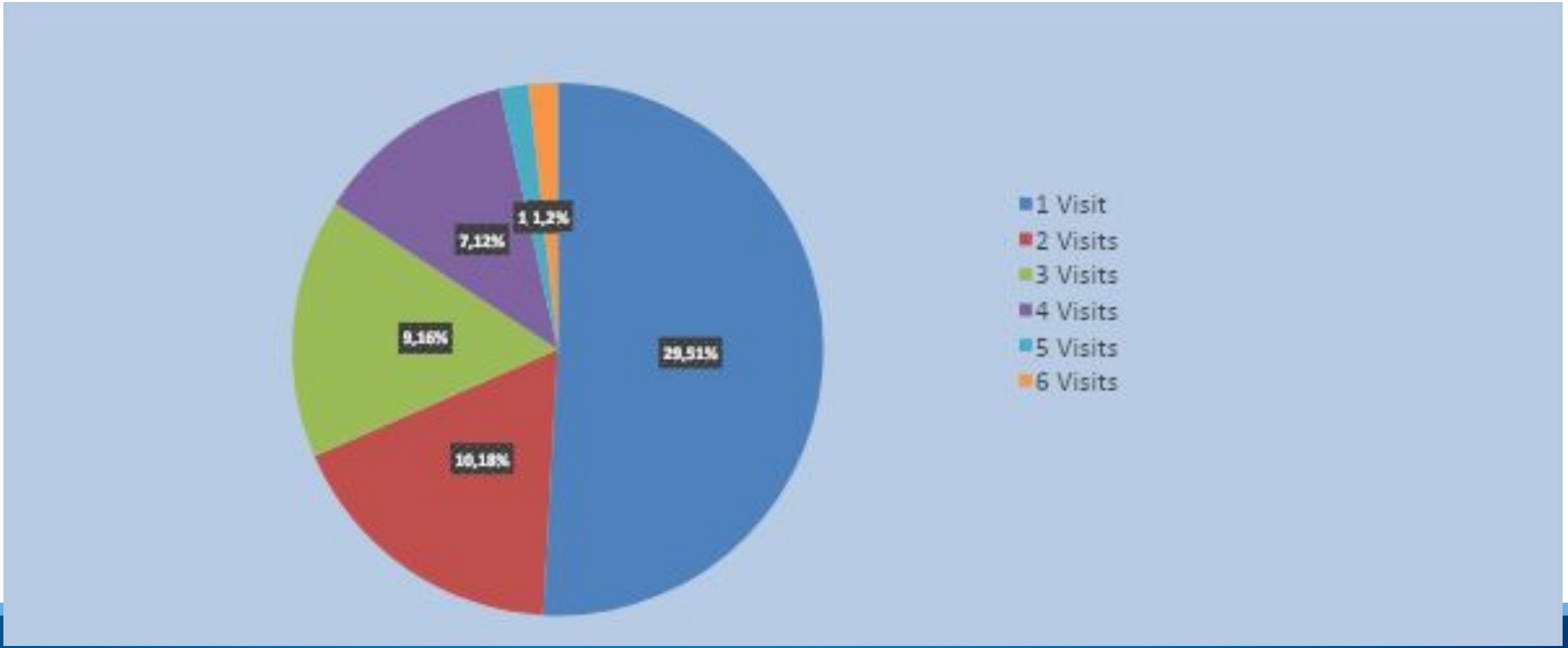
Telemedicine Utilization in an ALS Clinic

Methods

- Based on input from the ALS nursing staff regarding the burden of travel to patients and caregivers for in-person visits, selected ALS patients were offered two types of telehealth visits into their homes using Penn State Health OnDemand:
  1. Multidisciplinary visits with members of the ALS team on ALS clinic days
  2. 1-to-1 visits with individual ALS healthcare providers on other days.
- Metrics were recorded by the telehealth platform from October 2018 through October 2019

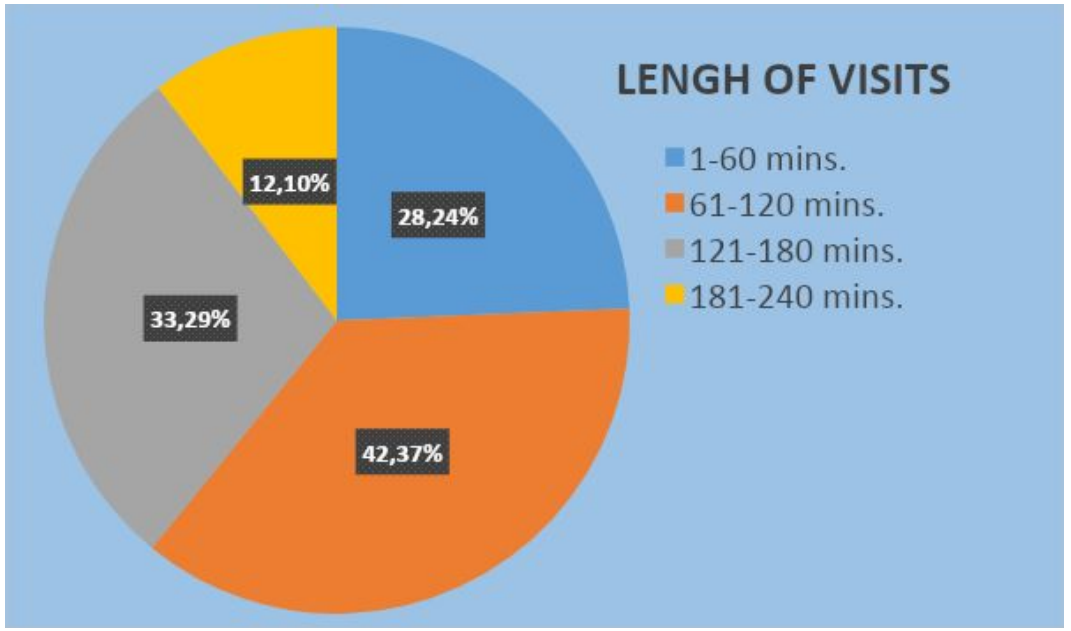
Results

Fifty-Seven patients and caregivers, 1 to 6 visits each = 115 total telehealth visits



Average visit length:
1 hour, 43 minutes.
Range 5 minutes to nearly 4 hours.

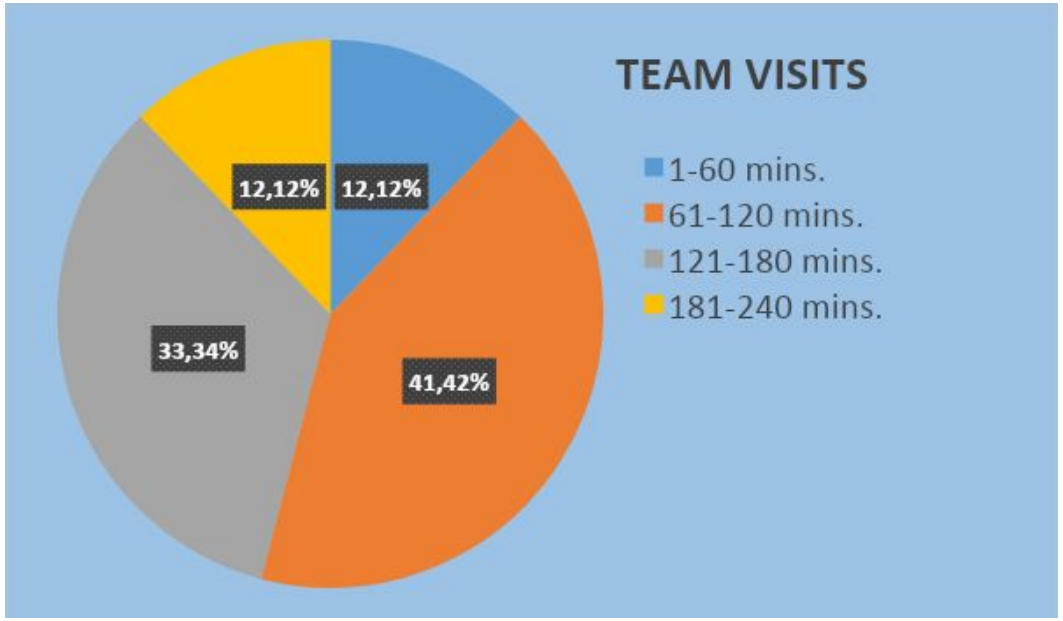
Average Visit Length	1 hr. 43 mins.
Min. Visit Length	5 mins.
Max. Visit Length	3 hrs. 51 mins.
Range of Visit Lengths	3 hrs. 46 mins.
Median Visit Length	1 hrs. 44 mins.



Number of monthly telemedicine visits ranged from 2 to 13

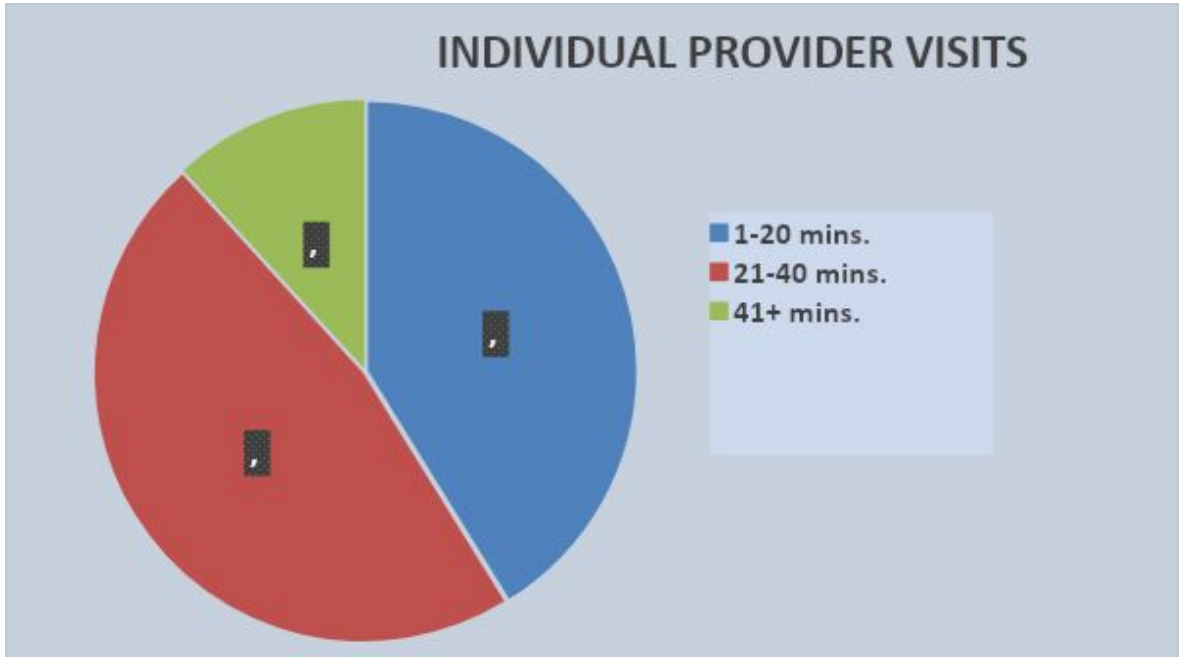
Ninety-Eight (85%) of these visits replaced in-person multidisciplinary clinic visits.

Average Visit Length	1 hr. 56 mins.
Min. Visit Length	7 mins.
Max. Visit Length	3 hrs. 51 mins.
Range of Visit Lengths	3 hrs. 44 mins.
Median Visit Length	1 hr. 53 mins.



Seventeen (15%) were individual healthcare provider visits

Average Visit Length	27 mins.
Min. Visit Length	5 mins.
Max Visit Length	1 hr. 50 mins.
Range of Visit Length	1 hr. 45 mins.
Median Visit Length	22 mins.

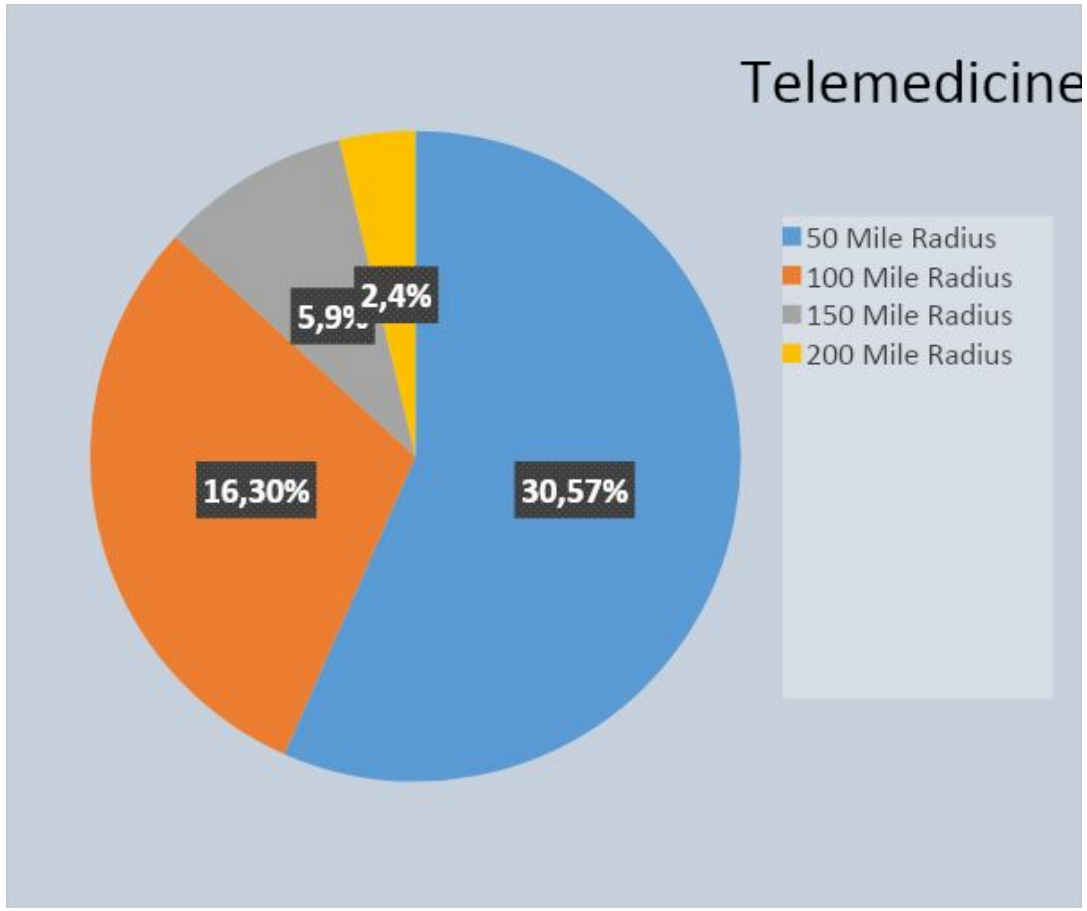


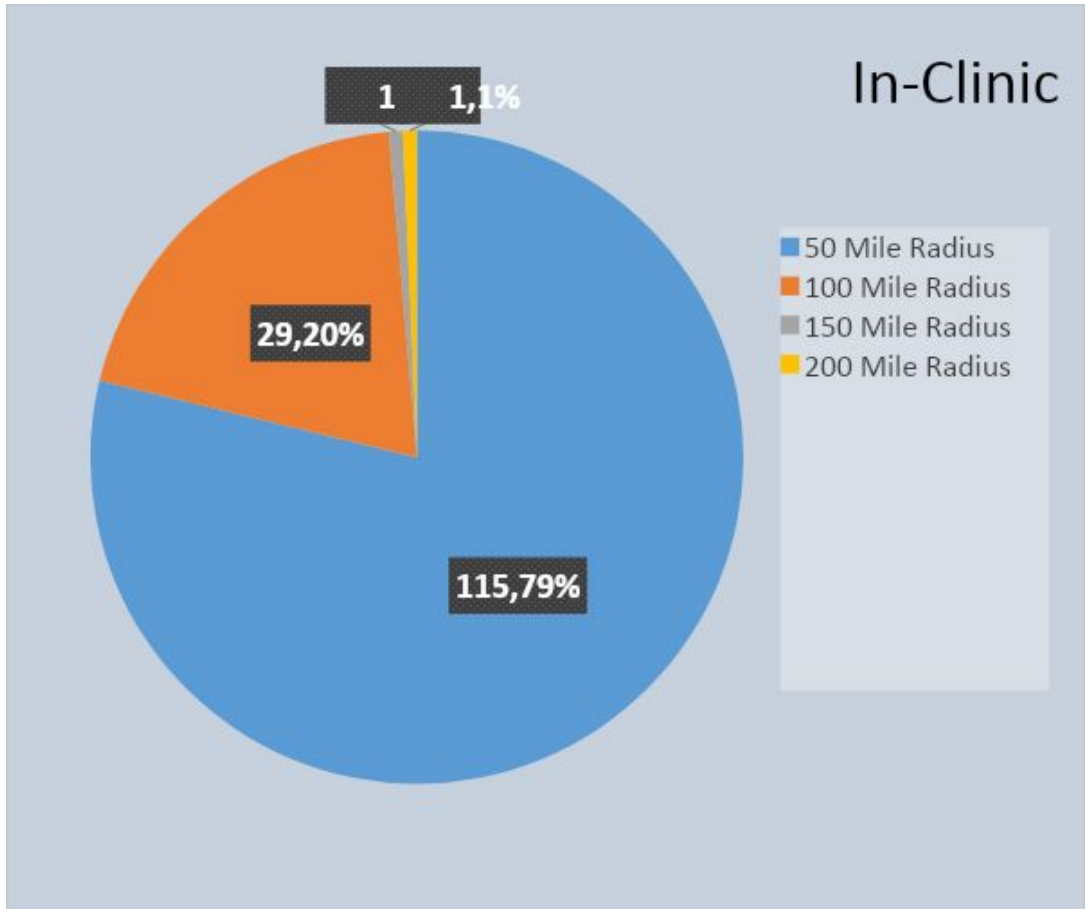
Distance to Clinic: Telemedicine vs. In-Clinic Patients

- Participating patients lived, on average, 52 miles from the ALS clinic (range: 7-188 miles).
- Approximately 13% had a travel distance to clinic of more than 100 miles
- Over 8,700 miles were s

- Patients who had in-person visits over the same period lived an average of 35 miles from the clinic. Only 1.4% had a travel distance to ...an 100

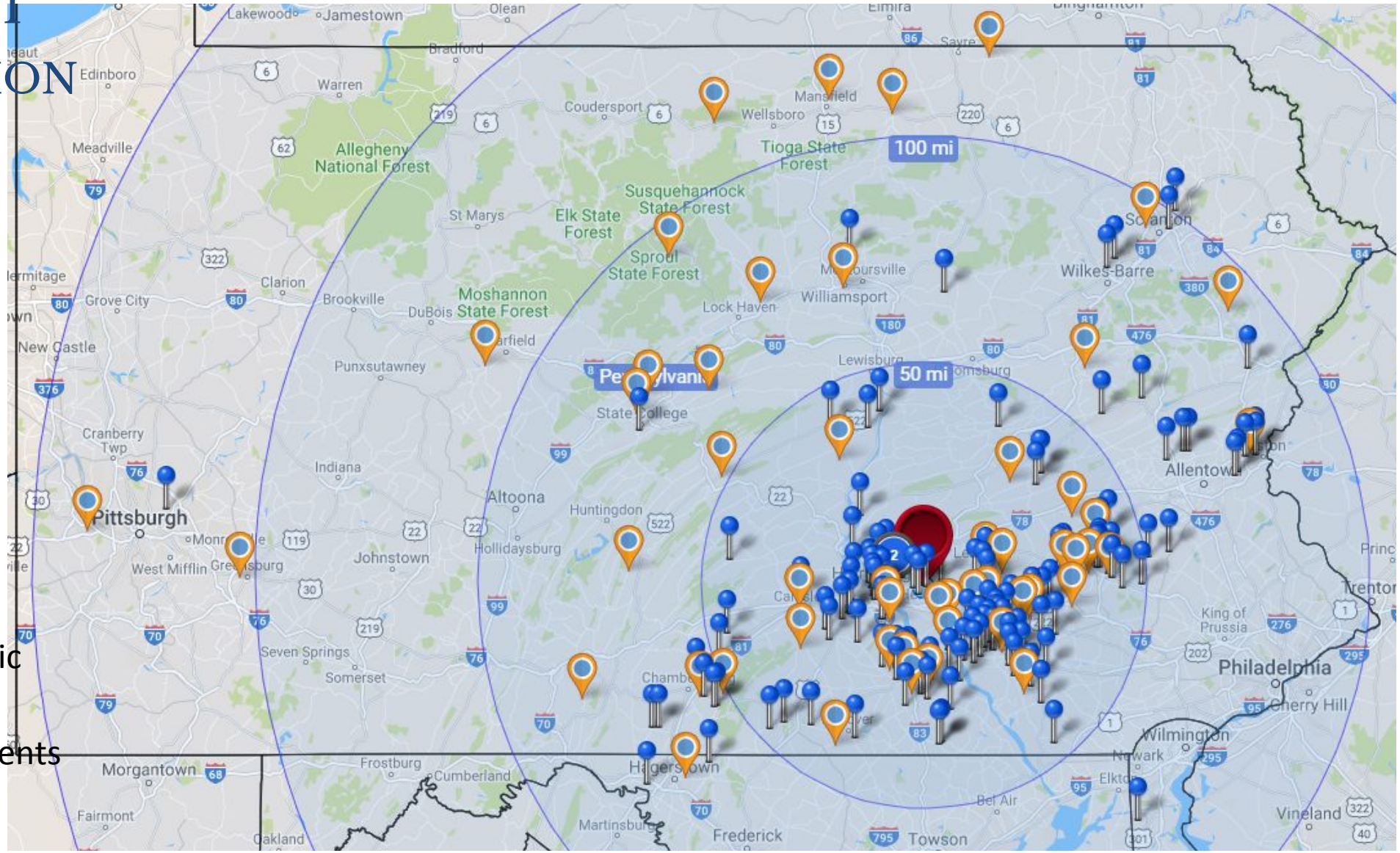
Distance to Clinic: Telemedicine vs. In-Clinic Patients





- Patients who lived farthest away, and those from more rural areas, appeared to be over-represented in the telemedicine vs. in-clinic group

Patient Location



ALS Clinic

Clinic Patients

TeleALS Patients

Discussion

- Telemedicine provided a viable alternative for ALS care for those patients unable or unwilling to travel to ALS clinic.
- It was used in place of both multidisciplinary and 1-to-1 visits.
- Telemedicine patients generally lived at a greater distance from ALS clinic than those making in-person visits, supporting the use of this platform for those for whom travel would be the greatest burden.

Predictors of Telehealth Utilization for ALS Clinic Patients

Methods

- Beginning in November 2017, all patients seen at the Penn State Hershey ALS clinic were offered participation in a study of telemedicine, but were not required to use it.
- Comparisons were made between enrolled patients who had at least one telemedicine visit and those who did not

Results

Enrollment

114 patients were enrolled

One-third (38) of patients participated in a telemedicine visit

Patients with at least 1 telemedicine visit had lower physical and respiratory function and were more likely to use NIV than patients who never had a telemedicine visit

	At least one telehealth visit (n=38)	No telehealth visits (n=76)	p-value
ALSFRS-R score (mean)	21.4	28.1	< 0.001
FVC % predicted (mean)	52.9	64.5	0.012
Age (mean)	62.0	61.9	0.672
Disease duration in years (mean)	1.6	1.9	0.255
NIV use	21/35 (60.0%)	15/60 (25.0%)	0.001
Gender	68.4% male 31.6% female	42.1% male 57.9% female	0.008
Hospice	7/38 (18.4%)	12/63 (19%)	0.938
Gastrostomy/PEG	10/38 (26.3%)	16/63 (25.4%)	0.918
Tracheostomy	3/38 (7.9%)	3/63 (4.8%)	0.405
Needing assistance to travel	29/36 (80.6%)	48/75 (64.0%)	0.077
Comfortable or very comfortable with technology	30/38 (78.9%)	49/75 (65.4%)	0.136

Those Living Farthest Away Were More Likely to Use Telemedicine

Travel time to ALS clinic	At least one telehealth visit (n=38)	No telehealth visits (n=75)	p-value
< 30 minutes	3 (7.9%)	9 (12.0%)	0.748
30-59 minutes	8 (21.1%)	19 (25.3%)	0.640
60-89 minutes	11 (28.9%)	25 (33.3%)	0.669
90-119 minutes	3 (7.9%)	10 (13.3%)	0.539
≥ 120 minutes	13 (34.2%)	12 (16.0%)	0.028

- A larger percentage of patients with at least 1 remote visit lived 2 or more hours from clinic.
- Remote visits were common for patients living farthest away
  - 52% living ≥ 2 hours from clinic had a telemedicine visit, compared to 25% living < 30 minutes away.
  - All patients with 4 or 5 video visits lived at least 1 hour from clinic

Discussion

- Patients with lower physical and respiratory function are more likely to utilize telemedicine
- Patients who live farther from clinic may use telemedicine more frequently than patients who live closer

Telemedicine Appears to Be Cost Effective

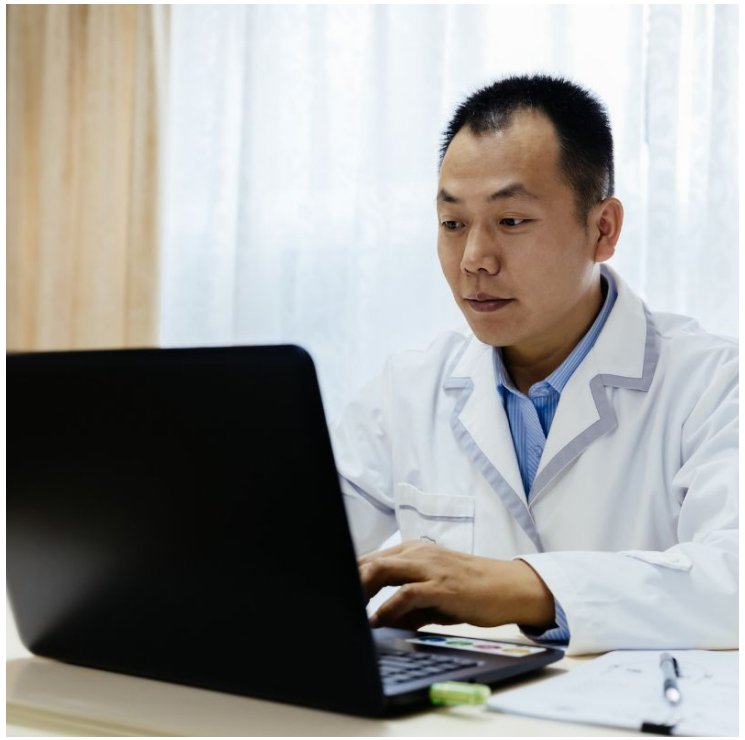
Telemedicine Appears to Be Cost Effective

- Comparison of cost of telemedicine visits for patients in their homes vs. cost of multidisciplinary clinic visits.
- Video televisits provide marked adjusted cost savings for patients and institutions under a variety of different assumptions.

Source: Paganoni S, et al. Muscle Nerve 2019;60:147-154

Asynchronous Telemedicine

Store and Forward Model



High Patient Satisfaction and Generally High But More Variable Provider Satisfaction

- A nurse was trained by members of the ALS team to perform a home multidisciplinary assessment
- Nurse traveled to patient's home and performed assessment.
- A video and audio recording was made of the assessment
- Healthcare providers on the team reviewed the assessment later.
- Providers made care recommendations to the clinic director.
- Clinic director formulated a plan.
- Plan conveyed to patient by nurse via video conference or telephone call.

Source: Pulley MT et al. Muscle Nerve 2019;59(1):34-39

Home Monitoring of Respiratory Function: Remote PFTs

Geronimo A, Simmons Z. Evaluation of remote pulmonary function testing in motor neuron disease.

Published in Amyotroph Lateral Scler Frontotemporal Degener 2019

The Role of Noninvasive Ventilation (NIV) in ALS

- AAN guidelines recommend considering the initiation of NIV for MIP that is weaker than -60 cm water or for FVC less than 50% of predicted.
- NIV in ALS prolongs survival, slows rate of respiratory decline, and positively impacts HRQoL for sleep, physical fatigue, and depression.
- Regular pulmonary function tests (PFTs) are a routine part of the ALS clinic evaluation and part of the ALS quality measures of the AAN
- When ALS clinic visits are performed remotely via telemedicine, patients must be transported to a facility for PFTs. This increases the burden of telemedicine visits and undercuts the goal of providing care in the home.

Methods

- Inclusion criteria:
  - Patients with ALS, PLS, or PMA from our institutional ALS clinic.
  - No cognitive impairment.
  - ALSFRS-R score of 2 or more on all items for speech, swallowing, saliva.
- Patients performed PFTs (forced vital capacity [FVC] and maximum inspiratory pressure [MIP]) with a respiratory therapist on clinic day.
- Same day, in another clinic room, they performed simulated remote PFTs.
  - In room were computer with monitor, and equipment identical to that we anticipated eventually using for performing FVC and MIP at home.
  - At the other end of the live video connection was a respiratory therapist coaching them
- Analysis was performed on the best of 3 responses

Accurate and Acceptable

- High correlation of remote PFTs and standard assessments
- Acceptability by patients and Respiratory Therapists was high

Next Step: More Frequent Assessment of Respiratory Function Using rPFTs

ALS Respiratory Monitoring Currently Does not Align with Patient Needs

- The Rate of Change in FVC in ALS is Markedly Heterogeneous
  - There are slow, moderate, and fast progressors
- But…The Clinic Model is Homogeneous
  - PFT's every 3 months is based on the usual model of ALS care
  - More frequent PFTs might permit earlier initiation of NIV
  - rPFTs could be performed more frequently than clinic or facility PFTs

What if we completed rPFTs each month?

- Of 217 patients for whom we reviewed FVC records, 144 experienced decline of FVC below 50%
- 100/144 would have had earlier initiation of NIV with rPFTs monthly

Next Steps

- Patient care: We have initiated more frequent rPFTs in selected patients.
- Research: We are planning to more carefully explore outcomes in patients undergoing more frequent rPFTs.

Gait and Falls

Another Area Where Telemedicine May Improve Patient Care

Background

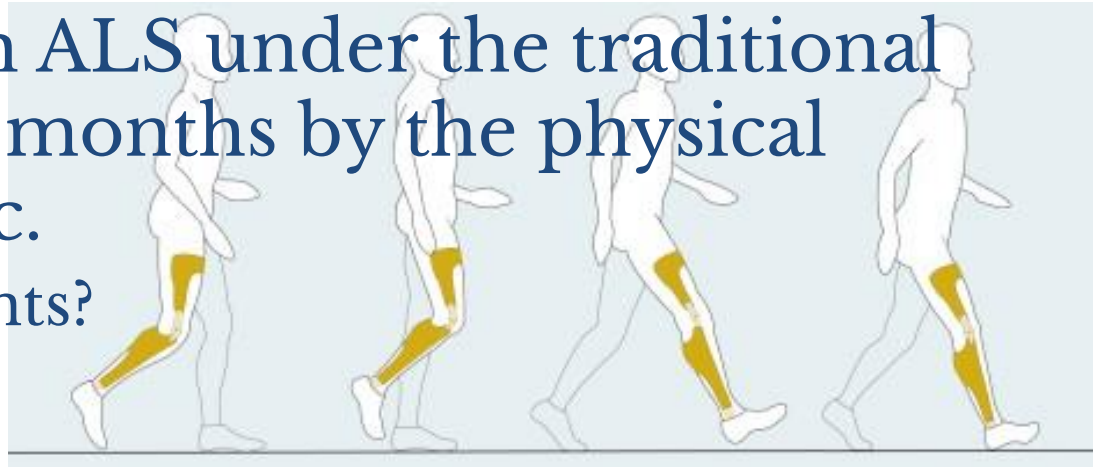
- Patients with ALS fall, and the consequences may be profound
- Assessment of fall risk, with the goal of preventing or at least reducing the frequency of falls, is an important part of ALS care.
- One of the ALS qua ed by the AAN is querying patients fo e past 12 months.

Y

- The rate of falls in ALS has not been clearly established.
  - Rates range from 0.05 to 0.2 to 1.8 falls per patient-month.
- Self-reporting of falls is compromised by recall bias, resulting in low sensitivity and underreporting of fall events.

Gait Assessments of Patients with ALS

- Individuals with ALS have gait measures that differ from healthy controls
- Increased and highly variable gait cycle time (time to complete a full walking cycle)
- Reduced stride length with increased variability in stride length
- Gait assessment of individuals with ALS under the traditional model of care occurs once every 3 months by the physical therapist in multidisciplinary clinic.
  - Can we obtain more precise assessments?



Methods

- We piloted the use of a wearable sensor as a way to provide regular estimates of step length, duration, and walking speed
- 30 patients, most with ALS, but a few with PLS or PMA
- All evaluations were performed during ALS clinic visits
- Patients wore sensors to detect accelerations and rotations of the body during therapist-guided walking
- ALSFRS-R walking subscore (FRSw) (a single question on the ALSFRS-R) was recorded.

Conclusions

- Step length and duration measured from a short period of normal walking correlated with functional measures of ambulatory health (FRSw).
- Implemented in the home, gait tracking could support physical therapy to reduce fall risk by allowing for evidence-based and timely decision support regarding safe mobility.

Next step: Home assessments of gait of patients with ALS using wearable devices

Beginning Enrollment:

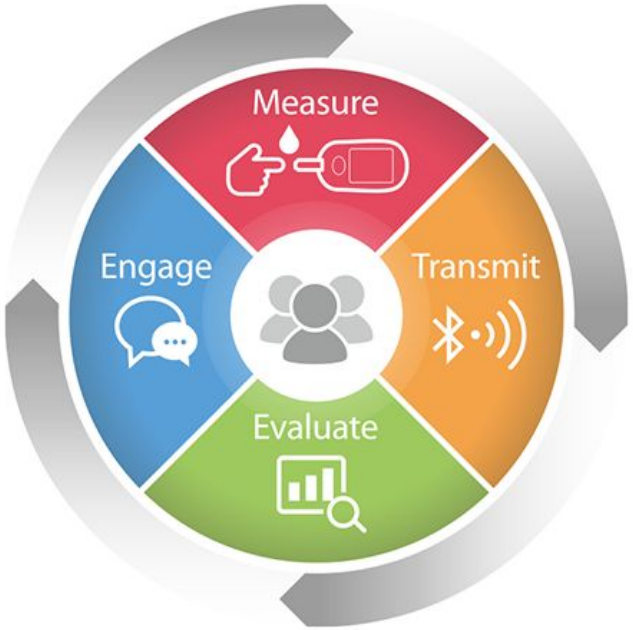
- Single Center Study

Speech and Swallowing: Early Exploratory Studies

- Voice recording and analysis:
  - As a marker of disease progression
  - As a surrogate for swallowing or respiratory function
- Microphonic recordings of swallowing
  - As a marker of bulbar function

Frequent Electronic Collection of Clinical or Research Data

Without In-Clinic Visits



The TiM System

- Development of an app for a tablet computer
- Patients and caregivers receive weekly questions related to limb function, bulbar function, nutrition, respiratory function, and “wellbeing”.
- Caregivers communicate about strain, depression, anxiety.
- Wi-fi enabled scales communicate information about weight.
- Information is displayed for the clinician in a clinically useful way, tracking trends in weight, caregiver strain, and other measures.

Source: Hobson EV, et al. Amyotroph Lateral Scler Frontotemporal Degener 2018;19:351-361.

ALS AT HOME: App for Smartphones

- Aim – Pilot a data collection system to permit in-home data collection for clinical trials
- Goal is to decrease the burden on patients and caregivers.
- Measures performed at home and transmitted electronically:
  - Handgrip dynamometry
  - Spirometry
  - Electrical impedance myography
  - ALSFRS-R
  - Separate speech app. Patients speak specific phrases into the phone. These are automatically uploaded to a separate cloud-based repository for analysis.

Source: Rutkove SB, et al. Amyotroph Lateral Scler Frontotemporal Degener 2019;20:61-67.

The All-Electronic Process Can Facilitate Study Enrollment

- Participants were recruited via on-line resources:
  - CDC ALS patient registry (https://www.cdc.gov/als/)
  - ALS Association and the Muscular Dystrophy Association websites
  - Advertisements in Facebook and Google
  - Social media: Facebook®, Twitter®, and Reddit®
- Diagnosis confirmed by review of records
- Patients consented, enrolled, and trained on-line
- Potential to reduce patient burden, increase enrollment

The COVID-19 Pandemic Led to an All-Telehealth ALS Multidisciplinary Clinic at Penn State

- From mid-March through early June, our ALS center saw patients in-person only for new diagnostic evaluations.
- All patients with an established diagnosis of ALS were seen only via telemedicine.
- If PT or OT or speech therapy were needed, we attempted these remotely or sent in-home services to patients' homes.
- The results of this are being analyzed with regard to the satisfaction of patients, their caregivers and our healthcare professionals.

Re-Establishment of In-Person Multidisciplinary Care

- We have now begun seeing established patients in person once again, but telemedicine has changed our model to reduce the in-clinic time for in-person visits:
  - The ALS nurse performs a telemedicine visit a few days before the multidisciplinary clinic appointment.
  - The social worker always carries out their visit via telemedicine.
  - Pulmonary function testing is performed either via home PFTs or locally or at our facility prior to the clinic appointment

Balancing In-Person with Telemedicine Multidisciplinary Care

- Some ALS clinic days are all-telemedicine, and others are all in-person
- Currently, about 20-25% of our ALS patients are being seen via telemedicine, and about 75-80% in-person.

Barrier to Telemedicine: Licensure

- Practitioners providing services via telehealth must be licensed in the state where the patient is located.
- Exceptions to this have been made on a state-by-state basis as a result of the COVID-19 pandemic. The long-term consequences are not yet clear.
- To expedite the practice of telemedicine in other states, many states have now joined the Interstate Medical Licensure Compact (IMLC).

Barrier to Telemedicine: Billing

- Medicare and most insurers began to reimburse for telemedicine visits during the COVID-19 pandemic. Whether this will continue is unclear.

Conclusions

1. Traditional in-clinic ALS multidisciplinary care is valuable, but poses a substantial burden for many patients and caregivers due to time and travel requirements.
2. Synchronous videoconferencing appears to be a viable adjunct to in-clinic care for individuals with ALS
   - It is feasible, acceptable, and may be associated with outcomes at least equivalent to traditional multidisciplinary care.
3. Telemedicine can be incorporated into a busy ALS clinic.
   - Most likely to be used by those with lower physical and respiratory function, and those who live farther from clinic.

Conclusions 2

4. Telemedicine is cost effective.
5. Telehealth be used for the remote collection of clinical and research data, including respiratory function, gait, falls, handgrip strength, weight, and speech.
6. Licensure and billing remain barriers, but are being addressed.
7. Further development of in-home data collection should enhance the abili viders to care for individuals with